

HRSA Care *ACTION*

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

Women and HIV/AIDS

Introduction

Between 120,000 and 160,000 women are living with HIV disease in the United States today (1). More than one-half do not know their own serostatus or that of their partner (2). Many will not be tested for HIV until they seek prenatal care, give birth, develop an AIDS-related illness or until their partner develops an AIDS-related illness (3, 4).

The health status of HIV-positive women in care compares poorly to that of HIV-positive men. They have higher viral load counts and lower CD4 counts when they enter care (3, 5). They are less likely to be seen regularly by an experienced clinician, less likely to be on antiretroviral therapy, less likely to be on a three-drug combination, and less likely to be taking a protease inhibitor (5, 6, 7, 8).

The incidence of HIV is increasing among women. In 25 States with integrated HIV reporting systems, new infections among women increased 15.7 percent in 1997 over 1996 (9, 10). While women represent 17 percent of AIDS diagnoses from January 1994 through June 1997, they represent 28 percent of HIV diagnoses in the same period (9, 11). Although African American and Hispanic women account for only 25 percent of the U.S. female population, they represent approximately 80 percent of new AIDS cases among women (9).

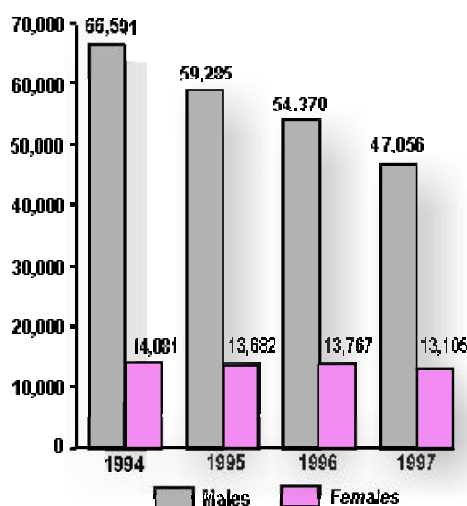
Circumstances That Determine Need

Parenthood and care-giving The needs of approximately 62 percent of HIV-positive women in the United States are fundamentally differentiated from those of others by a single fact, according to the CDC: they are mothers of at least one child under age 20.

The first priority of these women is their children. To grasp the circumstances of HIV-positive mothers—many of whom are also caring for a partner—one expert has suggested that individuals first imagine any mother. Then, superimpose on her life and the life of her family the impact of HIV: social stigmatization and isolation, increasingly frequent illnesses, debilitation, poverty, intensifying anxiety about the happiness and the health of her children and partner whom may also be HIV-positive, guilt and depression about leaving children and loved ones behind, and fear of premature death.

Lack of awareness of risk and serostatus Women often do not know the serostatus of their HIV-infected partner (4, 12).

New AIDS Cases in the U.S. (1997) By Gender



Source, CDC

Continued on Page 2

HEALTH RESOURCES & SERVICES ADMINISTRATION

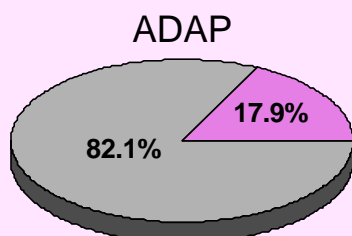
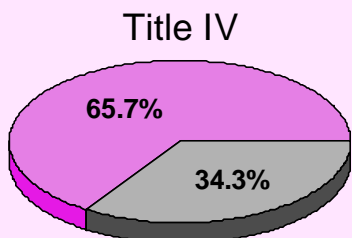
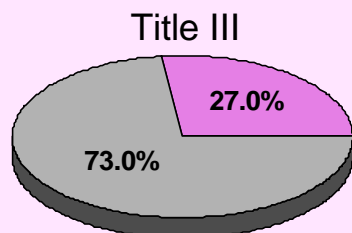
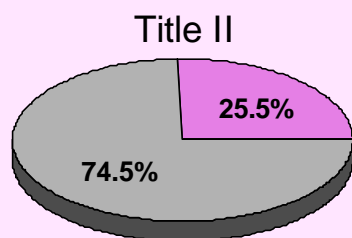
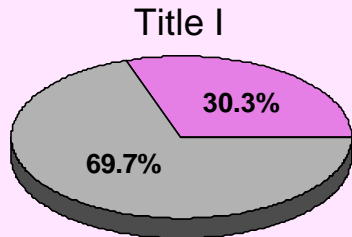
HIV/AIDS BUREAU

IN THIS
ISSUE

Clinical Care of Women Living with HIV Disease 4
 Four Perspectives From Women Serving Women 8
 IOM Panel Recommends Routine HIV Tests for Pregnant Women 12
 Insert: Calendar of Events

Ryan White CARE Act Clients

By Gender, 1996



■ Males ■ Females

Source, HIV/AIDS Bureau

Continued from Page 1 . . . WOMEN AND HIV/AIDS

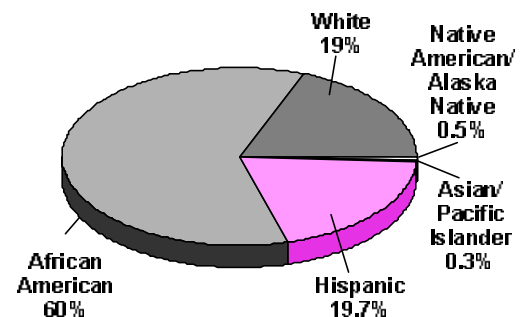
One-half of all women who are already HIV-positive do not know their serostatus. Many of these women do not even suspect that they are at-risk and neither do their healthcare providers. In one study at a large, urban medical center, "...if testing had been restricted to women with recognized high-risk factors, only 57 percent of the HIV-positive pregnant women would have been identified" (12).

Discrimination All persons living with HIV disease live with the threat of discrimination because of their HIV status. The 80 percent of women living with HIV disease who are minority also live with racial discrimination. Discrimination reduces access to prevention messages and healthcare, which is reflected in HIV incidence rates and health indicators among minority women: African American and Hispanic women are less likely than Caucasian women to have had an outpatient visit in the past six months, or to receive prophylaxis for opportunistic infections (7, 13). African American women ages 16 to 21 have an HIV prevalence rate seven times higher than Caucasian women and eight times higher than Hispanic women in the same age group (14). The effect of race and ethnicity on access to prevention messages, the incidence of co-morbidities and risk factors for HIV, and on barrier to care must be addressed in any initiatives for reducing HIV infection among women and improving the health status of those already living with the disease.

Poverty HIV/AIDS among women in the United States is, to a large degree, related to an epidemic of poverty and its associated problems. Most women with HIV were poor before becoming infected and will become poorer as their disease progresses (8, 15). A Maryland Medicaid study showed that 75 percent of the HIV-positive women who receive Medicaid did so before they were diagnosed with HIV (16). A study in one EMA indicated that "... among women and minorities, HIV infection is associated with preexisting economic distress" (15). A study of women from four urban areas in the Northeast indicated that 72 percent had incomes of less than \$1,000 per month (13). For women in severe poverty, HIV is not always the most important stressor and they are likely to devote their energies to addressing immediate needs of food and housing for their family over medical care for themselves, particularly if they are asymptomatic.

AIDS Among Females in the U.S.

Cases Reported in 1997, by
Race/Ethnicity



Source, CDC

Poverty may be increasing among some HIV-positive women. Some CARE Act-funded providers have reported an increase in demand for uncompensated care associated with changes in public assistance laws and the movement toward Medicaid managed care. Few HIV-positive women in the United States are privately insured; historically, the majority have been eligible

for Medicaid. However, today only pregnant women in poverty automatically qualify for Medicaid, although some States add provisions for women who are not pregnant.

For an HIV-positive woman who is Medicaid-eligible, Medicaid managed care sometimes can force a difficult choice. Should she seek care through a Medicaid managed care system that does not include providers experienced in treating HIV-positive women? Or, should she turn to an AIDS service organization outside the Medicaid managed care system that she cannot pay, but which has the necessary expertise to provide the care she and her family need? (See *HRSA Care ACTION*, “Managed Care and HIV/AIDS,” June 1998).

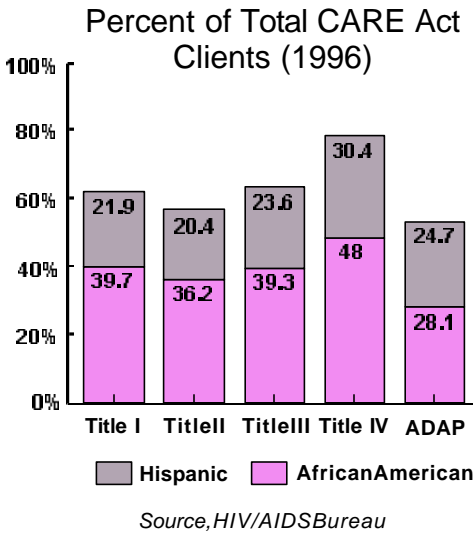
Aid for Families with Dependent Children (AFDC), an entitlement, has been replaced with Temporary Assistance for Needy Families (TANF), a block grant program. As a result, some poor HIV-positive women will lose financial support because TANF benefits are time limited, because they may not meet the State’s qualifications, or because they cannot comply with the TANF work requirements (16).

Psychological Distress, Violence, Substance Abuse, and Other Factors Among HIV-positive women, psychological distress is a barrier to coping. In one study, 31 percent of women who tested positive for HIV delayed care for three months or longer because of fear, depression, and anxiety about their serostatus (3). Psychological distress among women is compounded by high incidences of poverty, discrimination, care-giving responsibilities, addiction, and violence (18). Of 2,000 women enrolled in the National Institutes of Health Women’s Interagency HIV Study, nearly 50 percent report a history of sexual abuse and 60 percent have been victims of domestic violence (16).

Clinical and Support Services for Women

Titles I, II, and III of the CARE Act target all those living with HIV/AIDS who lack access to care, and Title IV funds additional services especially for women, infants, children, youth, and families. Title IV, whose clients are predominantly of color, funds 48 grants in 26 States, the District of Columbia and Puerto Rico. Grantees provide clinical care through a family-oriented approach that addresses the effect of HIV on families and increases the likelihood that clients will stay in treatment.

African Americans and Hispanics



Substance abuse remains a prominent problem among women with HIV disease and those at risk, and merits attention outside the scope of this article (See *HRSA Care ACTION*, “HIV/AIDS and Substance Abuse,” April 1998). In the mid-1990s, injection drug use dropped to the second leading risk factor for women diagnosed with AIDS. Yet, 32 percent of new AIDS cases in 1997 were transmitted through IDU and the majority of cases transmitted to women through heterosexual contact involved a sexual partner who contracted HIV through IDU. The use of both injected and non-injected substances leads to lower health care utilization and the effect of substance use on adherence is currently being debated.

Delivering Quality Care to HIV-Positive Women

Despite increased attention in recent years, HIV-positive women in care are less likely than men to receive the current standard of care (5, 7, 17). They are less likely to know their viral load or CD4 count, and their medical charts are less likely to contain this information (17). Women in care are less likely than men to have had a primary care consult in the past six months, and are less likely than men to receive prophylaxis and

antiretroviral therapy.

Women tend to receive care from less experienced providers—a critical problem, since provider expertise and experience directly affect quality of care and disease progression (5, 8). It is clear that efforts to communicate

Conditions for Retaining Women in Care

- The risk for HIV must be perceived.
- HIV status must be known and the need for medical care understood.
- Care-giving responsibilities must be met.
- Basic life needs for food, shelter, and community must be met.
- Treatment for other problems including substance abuse and mental health disorders must be ongoing.
- Transportation to appointments must be available.
- Child care must be available.
- Financial means to pay for care must be available.
- The patient must encounter medical personnel qualified to treat HIV infection in women.
- The patient must encounter care that is “family-centered”—care that addresses the impact of HIV and barriers to care for the family.
- The patient must encounter care that is “coordinated” to reduce the logistical problems of accessing care for an entire family.
- All prescribed medications must be available.
- Informational, psychological, and emotional support from peers and care providers must be ongoing.
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Continued from Page 3 . . . WOMEN AND HIV/AIDS

those with providers who do not know that HIV-positive individuals should be treated by specialists must be enhanced.

Conditions Necessary for Receiving Care Research and experience indicate a set of conditions which facilitate HIV care for women (See box at left).

Among the most fortunate, all of these conditions are met through the individual's own resources. In other cases, the patient may need assistance in only one area. However, many women living with HIV disease cope with a combination of circumstances that they cannot manage on their own. These women require assistance on several fronts. The Ryan White CARE Act exists to mitigate these circumstances and then to deliver the best clinical care available.

The circumstances and unique characteristics of HIV-positive women have not always been clearly differentiated. Increasing understanding of these differences and enhancing responses to them will improve access, utilization, and quality of care for many women over time. Today, gender is a predictor of the rate of increase in HIV incidence, access to care, and health status. Therefore, much work is yet to be done on behalf of women living with HIV disease and those at risk.

References for this article are available on the HIV/AIDS Bureau web site <<http://www.hrsa.dhhs.gov/hab>>.

CLINICAL CARE OF WOMEN

RECENT DEVELOPMENTS

By Jean R. Anderson, M.D.

Adapted from “Report from Geneva: Women and HIV,” *The Hopkins HIV Report*, July 1998.
Referenced abstracts were presented to the XII World AIDS Conference in Geneva.

Perinatal Transmission

AZT Increasing evidence indicates that AZT is effective in reducing transmission between mother and infant. Reports from several countries using the Pediatric AIDS Clinical Trials Group (ACTG) 076 regimen, in which women are treated with AZT antenatally and intravenously during labor, followed by 6 weeks of treatment to the neonate, generally demonstrate reductions in transmission to 0 to 5 percent [Galvaao, Abstract 12155; Rakusan, Abstract 12157; Ciria, Abstract 23314; Fiscus, Abstract 33162].

Many emerging reports concern transmission following planned or unplanned digressions from the full 076 regimen. While the full regimen appears to be the most effective, maternal treatment seems to be the most important. Fiscus reported a 3.7 percent transmission rate in North Carolina with any maternal antiretroviral therapy (ART) as compared to 30.5 percent with no maternal ART (n=653). Giving AZT only to the infant was not particularly effective (transmission rate 26.7 percent), but numbers in this category were small [Abstract 33162].

Intrapartum and neonatal treatment only (without maternal antenatal treatment) were more successful, resulting in a transmission rate of approximately 11 percent.

A growing body of data links viral burden to maternal-fetal transmission. Lambert examined factors associated with perinatal transmission in 459 women enrolled in PACTG 185 (comparing efficacy of HIVIG+AZT vs. IVIG+AZT) [Abstract 23265]. In a multivariate analysis, only viral load was associated with transmission. Important factors not associated with transmission included mode of delivery, prior AZT use, gestational age, and duration of ruptured membranes. Transmission was 0 percent (0/48) when HIV RNA was <500 copies/ml.

There is some reassurance that women for whom therapy would be considered optional (low viral load and high CD4 count) may be treated safely with transient AZT monotherapy during pregnancy [Bardeguez, Abstract 12233].

Followup of 226 PACTG 076 participants revealed no difference between AZT and placebo recipients in progression to AIDS or death, with a mean followup of 2.4 years.

Incorporation of prenatal AZT into clinical practice has had dramatic benefits, as evidenced by two large observational studies. The North Carolina study [Fiscus, Abstract 33162] reported a decline in transmission from 25 percent in 1993 to 3 percent in 1997, and CDC data from 29 States monitoring pediatric HIV infection demonstrated that overall rates of perinatally acquired AIDS decreased by 44 percent from 1992 to 1995 [Lindegren, Abstract 23306]. A number of missed opportunities for using this therapy were identified. The CDC reported that, for children with perinatal HIV infection born in 1995 and 1996, only 88 percent of mothers were tested before delivery and only 62 percent of cases had received AZT [Lindegren, Abstract 23306]. Inadequate counseling/testing, poor or no prenatal care, and substance abuse appear to be the major problems. Knowledge of the results of the 076 study correlates with willingness to take AZT [Reiter, Abstract 60272].

Hankins and colleagues, in the Canadian Women's Study, found that the advent of perinatal transmission prophylaxis has not resulted in an increase in pregnancy rates, but elective abortions have declined as more HIV-infected women choose to continue their pregnancies [Abstract 24199].

Antiretroviral Therapy and Pregnancy Surprisingly few reports at the World AIDS Conference dealt with combination antiretroviral therapy in pregnancy, and none had results to report from many of the clinical trials of these combinations now in progress. A survey of PACTG sites found that only 6.1 percent of pregnant women received protease inhibitor over the past year [Bartlett, Abstract 32444]. Small case series of highly active antiretroviral therapy (HAART) in pregnancy generally reported reductions in HIV RNA to low or undetectable levels. The drugs were well tolerated, but adherence may be a special problem in the first trimester [Beckerman, Abstract 12151; Kramer, Abstract 12152; Morris, Abstract 32419]. On a more cautionary note, a Swiss review of 37 pregnancies with combination antiretroviral exposure noted adverse events occurring in 21/37 women and 17/30 babies; many of these were mild or of questionable relationship to the medications. Of possible concern, however, was a high rate of premature birth (11/30 infants) [Lorenzi, Abstract 32453].

Access to Research for Women, Infants, Children, and Youth

Clients may now participate in research even if they do not receive care at an AIDS Clinical Trials Group (ACTG) research site. Until recently, participation was possible only for those linked to the ACTG locations. NIH is providing funds and Title IV grantees are providing support services that further improve access for those who wish to participate in research.

Cesarean Section and Vertical Transmission Much publicized findings regarding perinatal transmission have come from several studies showing further reduced risk of perinatal transmission (in addition to AZT) with Cesarean section performed before the onset of labor or rupture of membranes. Mandelbrot found that, among 902 mothers receiving AZT, elective C-section was associated with less transmission than emergent C-section or vaginal delivery (0.8 percent, 11.4 percent, and 6.6 percent, respectively) [Abstracts 23272; JAMA 1198;280:55]. By multi-variate analysis, the adjusted odds ratio was 0.2 (95 percent CI 0.0,0.9) for elective C-section. Semprini, reporting on results from an international clinical trial of planned C-section at 38 weeks vs. planned vaginal delivery, found 3 percent transmission in those delivered by C-section vs. 10.3 percent delivered vaginally [Abstract 23599]. Finally, a meta-analysis using individual patient data from prospective European and North American studies with at least 100 mother-infant pairs ($n=8533$) found that elective C-section significantly reduced perinatal transmission rates independent of antiretroviral treatment (OR 0.4) [Read, Abstract 23603].

As impressive as these results sound, and contrary to the apparent "take home" message from many news reports, it is premature to recommend routine C-section for HIV-infected women. In none of the studies were women treated with antiretrovirals other than AZT, and viral load measurements were not reported. Furthermore, maternal mortality is increased fivefold with C-section; postoperative complications have been reported in 31 percent of HIV-infected women, three times more than in HIV-negative controls. The widespread use of this strategy in developing countries raises further concerns. It seems very possible, however, that a subgroup of women who are unable to achieve appropriate reductions in viral burden may reasonably consider the option of operative delivery. More study is needed.

Other Risk Factors For Vertical Transmission

Breastfeeding. There is new evidence that breastfeeding should be avoided when the mother is HIV infected. A Malawian study followed 1,012 HIV-uninfected infants (98% were breastfeeding) for a median of 32 months and reported a cumulative hazard of infection of 9.6 percent by 18 months of life, remaining constant over that time [Abstract 23270]. New projections of the global burden of perinatal transmission suggest that breastfeeding could account for up to one-half of newly infected children in 1998 [Nieburg, Abstract 13591].

Chemokines. Two reports [Philpott, Abstract 21107; Salvatori, Abstract 60834] suggest a role for the CCR5 receptor in perinatal transmission, with decreased transmission in the presence of a defective CCR5 allele; a third study by Principi found no such association [Abstract 12161].

Bacterial Vaginosis. In a large cohort of pregnant women in Malawi, the prevalence of bacterial vaginosis (BV) was 29

percent, and only 11 percent had normal vaginal flora. BV was associated with HIV seroconversion during pregnancy (adj OR 3.7), and perinatal transmission increased from 4 percent with normal vaginal flora to 28 percent with BV [Taha, Abstract 23347]. Despite the enormous progress in reducing perinatal transmission, the global burden of this problem remains staggering. It is estimated that as many as 816,000 vertically infected infants will be born in 1998 [Nieburg, Abstract 13591]. The overwhelming majority of these are born in developing countries where there is limited access to all of the therapies suggested above. Bridging this gap remains only a dream.

Natural History: Gender and Viral Load

Several intriguing studies have reported gender differences in viral load that could have implications for starting antiretroviral therapy. In a study from the ALIVE cohort, Sterling et al. looked at the natural history of HIV infection after seroconversion in women versus men [Abstract 13379]. When controlled for age and length of followup, women had consistently lower HIV RNA levels after seroconversion, and this difference persisted throughout followup. Initial median viral load after seroconversion was approximately 69,000 in men and 15,000 in women. Differences persisted in a subgroup of rapid progressors. In a second analysis from the ALIVE study, Farzadegan performed a cross-sectional comparison of viral load at baseline and a follow-up visit 4.6 years later [Abstract 13384]. Median viral load in women was approximately one-half that in men. A third study from Ontario examined viral load differences by gender in 5,826 individuals; when adjusted for antiretroviral treatment, a significant difference in viral loads remained [Brabazon, Abstract 42474]. Women had a lower median viral load and were more likely to have viral burden below detectable levels. With most studies showing no difference in pathogenesis or rate of progression by gender, these studies may prompt reconsideration of guidelines for initiation of antiretroviral therapy.

Genital Tract HIV

A number of studies presented at the XII World AIDS Conference examined genital tract HIV and added to the growing body of data indicating that the genital tract represents a distinct reservoir of infection. There may be more heterogeneity of viral sequences in the genital tract as compared to plasma [Philpott, Abstract 11169; Fang, Abstract 32279]. Differences in genotypes, quasi-species, drug-resistant mutations, and viral loads suggest that selected HIV variants are actively produced in the genital tract [Ellerbrock, Abstract 23442]. In two patients from the WIHS cohort, viral load was more effectively reduced and evolution of resistant mutants more limited in the genital tract as compared to plasma, and it is possible that there are different antiretroviral pharmacokinetics and different replication dynamics in the two sites [Fang, Abstract 32279]. In asymptomatic women from the HERS study (n=89), genital tract shedding was associated with lower CD4 counts and genital tract inflammation, independent of the presence of STDs [Mayer, Abstract 23450]. These findings have implications for treatment, as well as for prevention of sexual and perinatal transmission.

Human Papilloma Virus/Cervical Dysplasia The most common genital tract infection in HIV-infected women is human papillomavirus (HPV). Numerous studies have documented increased rates of lower genital tract neoplasia correlated with evolving immunosuppression in these women. Several reports in Geneva focused on the effects of viral load and antiretroviral therapy on HPV infections and cervical dysplasia. A small Italian study (n=40) examined the impact of HAART on genital warts [Giovanna, Abstract 22192]. After complete surgical treatment, relapse occurred in 0 percent, 10 percent, and 75 percent in patients treated with 3 drugs, 2 drugs, and no antiretroviral therapy, respectively ($p < 0.01$). There was a significant difference in viral load between patients with and without relapse. A French study of 85 women with advanced HIV disease who were started on triple combination therapy (including a protease inhibitor) and who were examined both cytologically and colposcopically, noted a decrease in SIL (cervical dysplasia) from 66 percent to 49 percent after a median duration of 5 months of therapy [Schmitz, Abstract 22312]. The prevalence of HPV did not change. In the WIHS cohort (n=1483) cervicovaginal HPV infection by PCR was common at all levels of HIV viral load and CD4 count. The prevalence was highest in women with CD4 counts $< 200/\text{mm}^3$ regardless of viral load but was also uniformly high when viral load was $> 100,000$ copies/ml. This suggests that low CD4 counts and high viral loads may both be important in the activation of HPV replication [Palefsky, Abstract 22313]. A similar association between viral load and HPV, as well as cervical dysplasia, was reported by Shah from the HERS cohort [Abstract 22317]. Finally, also from HERS, a small group of women who initiated HAART was compared with an equal number of women with similar baseline CD4 count and HPV infection status who did not take HAART [Duerr, Abstract 60289]. There was no difference in the two groups with respect to Pap smear results, acquisition of HPV, or persistence of HPV present at baseline, changes in the number of HPV types, or changes in the amount of HPV present after 6-12 months of follow-up. These studies suggest that HIV-infected women should continue to be followed closely for evidence of lower genital tract neoplasia regardless of ARV therapy or HIV RNA levels.

New Models of Care for Women

Seven Special Projects of National Significance grants are funding implementation of innovative models of care for women living with HIV/AIDS. Integration and coordination of care, care for substance abusers, client education, and counseling and testing are principal elements.

FOUR PERSPECTIVES FROM WOMEN SERVING WOMEN

I **Dorothy Mann** is Executive Director of the Family Planning Council in Philadelphia, which facilitates delivery of a broad range of services to women and families through a network of hospitals, clinics, and community-based organizations. The Family Planning Council is funded through a variety of sources, including Title IV of the Ryan White CARE Act.

Describe your patient population.

Most of the HIV-positive women we see are mothers. They are, by and large, poor women of color who got this disease primarily through IDU or sex with an IDU. These women need hot water, pest control, heat, refrigerators, funeral expenses—the things that the rest of America takes for granted. I remember a woman and child, now in our housing program, who had been relegated to a basement because they were HIV positive.

How do you get women the primary care they need?

What do you mean by “primary care”? Clinical care [for HIV] is not just basic primary care. If you have HIV, you need a specialist.

To get women the care they need, we recognize them as patients in their own right and as mothers. We help them help themselves, and respect their cultures. We support their role in the family and, simultaneously, we work to keep women in, especially for gynecological care. Most infectious disease doctors don’t know how to do a pelvic exam. You have a double whammy here with HIV and OB/GYN issues. Think about the reproductive health needs of HIV-positive women! How do they deal with decisions around having another child? How is their contraceptive behavior affected?

Our organization has put “assistant case managers” in place—women from the community trained to work with families in their homes. Assistant case managers have been trained to provide support on basic things: how to take a temperature, when to call the doctor, what some signs of illness are, how to recognize and describe symptoms. By training and employing women whom our clients perceive as “just like them,” our clients have become more sophisticated in dealing with their own personal health and the health care system. In our evaluation, women with this support went to the emergency room and to the hospital less. Basically, they were healthier.

How do you help your clients adhere to treatment regimens?

If you do nothing more than say “do this,” you are wasting your breath, so we continually “rehearse” and reinforce. The “rehearsing” has to be individualized and repeated over and over again. In the general population, patients tend to tell providers what they want to hear, and everybody knows that the vast majority of people who agree to finish their antibiotics don’t. An enormous amount of time and individualized attention are required to work through the importance of taking medicines, especially when more than one person in the household is on medications.

What changes in your client base have you seen during the last two years?

Today, more of our clients are uninsured. Also, more of our family planning clients agree to testing, since we supplemented our confidential testing with anonymous testing. This illustrates how sensitive women are to confidentiality. In the past 18 months, chlamydia has increased and we are testing more for it. IDU has not changed, but the need for mental health services has increased.

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Dorothy Mann

What is wrong with the way we have traditionally addressed the needs of HIV-positive women?

Our society tends to worry about women when they are pregnant, and not when they are not. The reason is that what we are really concerned about is the child. Our women know this. The structures put in place both in prevention and care were, for a long time, put there by men for men, and women are nowhere near caught up. When you come in second you are treated in a second class way. There is no question that we have done much more prevention work among teens and gay men than among women. For a very long time, most substance abuse prevention and treatment responded to the needs of men. Recently, our emphasis has been on pregnant women. So women as women get lost a second time.

Title IV has done a great job—and, yes, my organization gets a Title IV grant—of creating family-centered care, with the child as the index. The purpose has been to eliminate the need to go all over town for core services. But as a society, we have got to recognize HIV-positive women as mothers with a lot of basic needs including reproductive health needs.

Barbara Aranda-Naranjo is Senior Research Nurse, University of Texas Health Sciences Center San Antonio.

She is Assistant Director, South Terrace AIDS Center for Children and Families, which receives grants from Title IV, SPNS, and the State of Texas.

Does the Center serve primarily Hispanic families?

Yes, in most cases, we're providing care to a single, female head of household between 18 and 35, and her children. They all have at least one HIV-infected child.

Our clients are American citizens or legal residents, but most speak little English and their culture is more Mexican than American. Not one of them received regular primary care before testing positive. The primary transmission category has always been heterosexual contact.

Our families are very poor, and we are seeing more and more who are completely destitute. With the change in the laws, they have to work to get welfare, but most are too sick to work and not sick enough to get SSI. In Texas, applications to receive SSI are denied at least five times, anyway. Illiteracy is high. These families are completely dependent on charity.

Why is care for the "affected" so important?

These women see themselves as the primary caregiver for their families. They don't see their children as separate from them. The parent would feel guilty if they were getting

care, but their uninfected children were not. The parent would feel angry and hurt if they were told they could get care, but their child could not. They would be completely offended if you referred their non-infected child to another provider.

Most of our clients are living with HIV-positive significant others who refuse to get care. They know absolutely nothing about medical care or HIV. We have to deal with this because, in the Hispanic culture, women turn to their significant others to make decisions.

You are suggesting a very low awareness level of HIV.

Yes, and these individuals live with fear of everything, regardless of HIV, because of ignorance. The people live in unincorporated neighborhoods. We are using Title IV and SPNS money to promote health in these "Colonias," where there are no street signs, no addresses, no water, no lights. Our "promotores" go into these communities, develop trust, and then talk about basic health and prevention issues. We also collaborate with community-based organizations in these neighborhoods to reinforce what we say when we aren't there.

Do your clients have access to antiretroviral therapy?

For the moment, clients who choose to be on combination therapy are able to get drug through ADAP.

Women and Local Planning

Spending decisions for more than 60 percent of all CARE Act dollars are made by Title I Planning Councils and Title II Consortia. The HIV/AIDS Bureau is cooperating with the AIDS Policy Center to respond to the skills needs of women involved in local planning by developing a training curriculum that assures their full participation in the planning process.

However, there are rumors that the Texas ADAP will go to a lottery system because of a waiting list for drugs.

In our community, people still believe you can get HIV from mosquitoes or going into a swimming pool. One woman thought being HIV positive was a good thing, so didn't come back for care until she became symptomatic.

Barbara Aranda-Naranjo

Adherence is a huge problem. These individuals don't understand resistance or the need to see a doctor, partly for cultural reasons. In Mexico, individuals get drugs from pharmacists without ever seeing a physician. And in our area, they are accustomed to going to the emergency room for drugs "when they feel bad." The idea of taking medications when they feel OK is foreign.

These individuals are proud. You don't talk about your disease! You NEVER, in their culture, talk about anything where someone will lose face. So they want to keep their

health issues very quiet. It is very difficult for these women to be honest with their physician. They think it is safer if no one finds out they are sick.

Beatriz Grinsztejn is currently studying a cohort of 500 HIV patients, of whom about 200 are women at the Oswaldo Cruz Foundation Hospital in Rio de Janeiro, Brazil. The Foundation is the largest organization of its kind in Latin America. It includes Brazil's largest research institute, a hospital, a public health school, and several clinics.

Is the epidemic among women in Brazil relevant to what we face in the United States?

Actually, the similarities are striking. There are about 120,000 persons living with AIDS in Brazil but, as in the United States, HIV is not reportable. AIDS is growing among women and among the poor, and in the South, where it is growing among injection drug users. Most cases are located in the big cities—Rio, San Paulo, Brasilia.

The ratio of infections is 2:1 (men to women); in 1984, it was 32:1. Most are really poor. About 30 percent suffer domestic violence. Addiction is a problem in certain cities, but heterosexual transmission is the risk factor for most women in Rio. Most have significant others and children who are infected but, since 1996, we have really reduced transmission through AZT during pregnancy and labor.

What prevents women from getting care in Brazil?

The biggest problem is finding out who is HIV positive. Then there's the problem that OB/GYN specialists don't want to treat these poor, HIV-positive women, so they won't learn how. The quality of prenatal care is low. Physicians are not educated to talk about STDs.

Is testing readily available in Brazil?

Yes. We have many anonymous counseling and testing sites but they're underutilized. Women don't know they are at risk. Teaching women about HIV is difficult. Their educational level is low. Peer counseling and community work are not a tradition in Brazil and are just beginning. We use the media, but the church fights condom use and makes it very difficult to talk about sexuality. So, we are trying to educate the physicians first.

How?

Brazil is using a loan from the World Bank to fund basic HIV care training and to support a national training on vertical transmission. In some cases, there is a great deal of pressure from local authorities to get training, and in others there is not. Participation is never mandatory.

OB/GYN physicians are much less interested in training than primary care physicians. They are afraid they'll have to treat an HIV-positive patient. They are acting like many primary care doctors acted 15 years ago. This is a huge problem.

Do women have less access to care than men?

I don't believe that they have less access to care, but they have more difficulty continuing care. Women always have other responsibilities—children, in particular. From my point of view—and this is completely observational—women have more problems with adherence, dealing with side-effects and staying in care, because they are always taking care of someone else.

What helps keep them in care?

In my hospital we give them a bag of basic foods once a month. They have to come to the hospital to get it and then we see them. We also provide formula, milk, etc.

Are antiretrovirals available?

Yes. The government provides drugs, free of charge. South American countries collaborate to get bulk purchase discounts. Only efavirenz, nevirapine, and delavirdine aren't available and the Ministry of Health is in the process of buying them. There are about 300 distribution points for AIDS drugs nationwide, and all of them are within primary care provider sites.

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Beatriz Grinsztejn

Most of the women are on antiretroviral therapy. We begin antiretroviral therapy when the CD4 count is <500, or viral load is over 10,000. Most HIV patients are on PCP prophylaxis. Incidentally, the most significant opportunistic infection in Brazil is Tuberculosis.

Compliance is very bad. In Brazil, care is physician-centered. We don't have social workers to help with adherence. I am a specialist and spend 40-45 minutes with each patient, but many do not do this. If the physician is committed, it really helps. If not, it's a big problem.

Judith Walker is Director of the Douglas County Health Department in rural, northern Wisconsin. Previously, as education and case management coordinator, she served as the only HIV/AIDS case manager for Douglas and four surrounding counties.

4

Describe the five county area where you coordinated case management for people living with HIV.

The population of all five counties combined is less than 100,000. Unemployment is high. Most of our factories have closed. Our people depend on low-paying service jobs to make ends meet and lots of people have to work two or three jobs.

How many HIV-positive individuals do you serve?

At any given time we might be serving a total of 20 individuals in all five counties. About a third are women who almost always contract HIV through heterosexual contact with men who have worked and traveled outside our area. These women are typically young, low-skilled, and in

relationships with people who are also HIV positive. Almost all have children.

Women in our region typically become aware of their HIV status after they or their partner begin to show symptoms. Most do not have health insurance, so they don't go to a doctor unless they are really very sick or until they are in the second trimester of pregnancy. Women who do get care more regularly usually see physicians who never imagine that HIV could be an issue, so they don't test.

Can HIV-positive women get competent care locally?

Not the kind of care they need. None of the local physicians has had the case loads that generate broad experience in treating people with HIV. Some really bad mistakes have occurred here because of this. Many local physicians would prefer not to deal with HIV-positive patients. When we have offered training in the past, most of them haven't been interested.

Where do people go for care?

The majority travel to Duluth, Minnesota to get care from infectious disease specialists. Depending on where they live in our region, this can be 300 miles, round trip. I think, though, that even if qualified care was available here in our area, a lot of people would continue to go to Duluth, because they don't want anyone to know they are HIV positive.

So, the issue is quality care and confidentiality?

Yes. If you go to a local doctor or emergency room, people know it, and they know why. There is a lot of fear here, and the community does not understand HIV at all. Just renting a house or apartment in this area is really hard if the landlord knows you are HIV

Just renting a house or apartment in this area is really hard if the landlord knows you are HIV positive.

Judith Walker

Continued on Page 12

IOM Panel Recommends Routine HIV Tests for Pregnant Women

— Secretary's Determination Expected in December

A panel convened by the Institute of Medicine (IOM) of the National Academy of Sciences recommends HIV testing and notification of results for all pregnant women as part of the battery of standard prenatal tests. Under current Federal guidelines, doctors are encouraged to provide HIV counseling and suggest an HIV test. The IOM panel recommends that pretest counseling be reduced to diminish the burden on providers and that women be informed that they will be tested unless they specifically object.

The IOM provided its recommendations in fulfillment of statutory requirements. The Ryan White CARE Act Amendment of 1996, PL 104-446 section 2626(d), requires that the Secretary of the Department of Health and Human Services determine whether a set of interventions has become standard. Section 2628 requires the Secretary to request a report from the IOM before making the determination.

After reviewing the report, the Secretary must determine whether it has become routine practice in the provision of

health care in the United States to (1) test infants for HIV whose mothers were not tested during pregnancy; (2) adhere to statutory requirements for the disclosure of the infant's HIV test result to specific persons; (3) provide HIV counseling to persons receiving an infant's test result; and (4) provide results to pregnant women who have received prenatal HIV testing.

The IOM panel recommendation is controversial. Some experts favor testing of only those at highest risk. Others are concerned about the implications on the privacy of prospective mothers and the reduction of pretest counseling. At the time of publication, it was not known what determination the Secretary would make nor how the Congress would respond.

Continued from Page 11 . . . FOUR PERSPECTIVES FROM WOMEN SERVING WOMEN

positive. Most of the patients I've dealt with over the year have ordered medication through the mail to avoid gossip at the local pharmacy, and I don't blame them.

How do barriers impact quality of life for these women?

They live from one crisis to another, and their biggest problem is that they have too many roles. They are parents, care givers for their significant other, and often they are helping their parents.

They have to deal with pregnancy, getting kicked out of their apartment, problems with their children. And other things are constantly coming up. Dental problems, for instance. Even if we manage to come up with the money to pay for their dental care, most of the dentists in this area won't touch them.

What is the role of case management in your area today?

Case management has changed a great deal, since people are living longer. Instead of teaching people how to live with severe illness and cope with dying, we get them the services that they need to manage their daily lives. We help them make decisions around issues like pregnancy, birth control, and mental health.

Adherence, being such a major problem, receives a lot of our attention. We provide ongoing monitoring, and we work

with our patients to organize their lives in a way that makes adherence feasible. This is some of the most important work we do.

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